

Missouri Statewide Health Information Exchange

Consumer Engagement Workgroup

March 10, 2010

11:30 am – 1:30 pm

Jefferson City, MO



Agenda

Topic	Facilitator(s)	Time
Welcome, Introductions & Meeting Objectives	Co-Chairs	11:30 – 11:45 am
Advisory Board Report	Co-Chairs & Manatt	11:45 – 12:00 pm
Discuss Intersection with Governance Workgroup	Co-Chairs & Manatt	12:00 – 12:15 pm
“Straw People” <ul style="list-style-type: none">➤ Consumer➤ Meaningful Access➤ Consumer Advisory Council	Co-Chairs & Manatt	12:15 – 1:00 pm
Consumer Engagement Strategy Discussion	All	1:00 – 1:25 pm
Next Steps	Co-Chairs & Manatt	1:25 – 1:30 pm

Governor Nixon's Vision – Six Objectives

- 1. Improve the quality of medical decision-making and the coordination of care;**
- 2. Provide accountability in safeguarding the privacy and security of medical information;**
- 3. Reduce preventable medical errors and avoid duplication of treatment;**
- 4. Improve the public health;**
- 5. Enhance the affordability and value of health care; and**
- 6. Empower Missourians to take a more active role in their own health care.**

Thank you for partnering with the state in taking critical first steps in building a new framework for health information technology in Missouri

Meeting Objectives

- **Advisory Board Report**
- **Review and discuss “straw people”**
 - Definition of consumer
 - Meaningful access
 - Consumer Advisory Council composition –
confirm last meeting's discussion
- **Begin discussion of Consumer Engagement Strategy**

Meeting Recap

➤ **Content Reviewed**

- National Update – Funding Announcement
- Workgroup Progress Update (Other Workgroups)
- Operational Plan Requirements
- “Straw” People Definitions/Frameworks
 - Consumer
 - Meaningful Access
 - Consumer Advisory Council

➤ **“Consensus” – Key Decisions**

- Consumers should be part of the Statewide HIO and be formally represented on the Board.
 - The Consumer Engagement Workgroup is not comfortable with the Governance Workgroup's recent recommendation that a majority of the Board be constituted of providers, and at least two seats be reserved for consumer representatives.
 - Two consumer representatives on a Board of 20 members will likely not lead to sufficient representation; the Workgroup prefers that 25% of Board seats be reserved for consumers
 - No stakeholder group should be guaranteed a majority on the Board.
- There should be a Consumer Advisory Council established to inform and advise the Statewide HIO and its Advisory Board.
 - The Consumer Advisory Council should provide a potential slate of candidates to the Nominating Committee of the Board of Directors for consideration
 - At least one member of the Consumer Advisory Council should serve on the Board of Directors

Advisory Board Meeting Report

- **The MO-HITECH Advisory Board met on Thursday, February 25, 2010 to review and approve the Final Strategic Plan**
- **Key Outcomes**
 - ***The Advisory Board voted unanimously to approve the MO-HITECH HIE Strategic Plan for submission to ONC***
 - **The Advisory Board recommended**
 - The Governance Workgroup, in consultation with legal counsel, should
 - Move forward with the articles of incorporation
 - Begin drafting the bylaws of the Statewide HIO
 - Establish a process to vet and recommend members for appointment to the Board of the Statewide HIO
 - ***All Workgroups should consider and recommend candidates for the initial Board of Directors***

Advisory Board Report – Consumer Engagement

- **Advisory Board Discussion regarding discrepancy between Consumer Engagement and Governance Workgroup recommendations**
 - The Strategic Plan should remain at a high level, especially in the case of conflicting Workgroup recommendations
 - The Workgroups should define “provider” and “consumer” and corresponding skill sets for purposes of service on the Board of Directors
 - The Board will ultimately need to be willing to reexamine its portfolio to ensure it is engendering public trust; specifying quotas does not tend to facilitate trust
 - The process is not mature enough to warrant the recommendation that there be quotas or reserved seats on the Board
- **Advisory Board Recommendation: *For purposes of the Strategic Plan, exclude language specifying majority of providers and consumers, and quota that two seats be filled by consumers***
 - The Workgroups should revisit these recommendations during their next meetings

Letters of Support – Advisory Board Recommendation

- **Individuals or organizations who have been active in the Strategic Planning process are invited to send a *Letter of Support* to ONC**
- **Sample text**
 - “On behalf of [ORGANIZATION'S NAME], we endorse and support the Strategic Plan that was recently submitted to the Office of the National Coordinator for Health Information Technology (ONC). This roadmap will allow Missouri to reach its goals for effective and secure exchange of health information, thereby improving health and healthcare of all Missourians.”
- **Copies of the letter are available electronically online at <http://dss.mo.gov/hie/action/index.shtml>**
- **Please complete and return letters to Charlotte Krebs asap – ckrebs@primaris.org**

Definition - Consumer

➤ Merriam-Webster – consumer

- Pronunciation: \kən-☐ sūmə^r\
- Usage: *often attributive*
- : one that consumes: as a : one that utilizes economic goods b : an organism requiring complex organic compounds for food which it obtains by preying on other organisms or by eating particles of organic matter

Function: *noun*

Date: 15th century

➤ Examples

- National Partnership for Women and Families
- Australian Government
- U.S. Food & Drug Administration

➤ Suggested “Straw” Person Requirements

- For purposes of service on the Board of the Statewide HIO, a consumer representative should exhibit the following characteristics:
 - Affiliation with a nonprofit, mission oriented organization(s) that represent a specific constituency of consumers or patients
 - Established relationships with the community (e.g. media, policymakers, and elected officials)
 - Capable of reflecting the viewpoints and concerns of consumers and patients
 - Person in whom consumers and consumer organizations have confidence
 - Background in health care or understanding of the health care system
 - Others?



National Partnership for Women and Families – Aligning Forces for Quality

- **Definition of an Individual Consumer** – A consumer is an individual who has significant personal experience with the health care system, either as a patient or caregiver.
 - While there is great value in engaging consumers and patients, most individual consumers lack the ability to influence and communicate with a large network or constituency.
 - *Engaging both individual consumers and consumer representatives is recommended.*
- **Definition of a Consumer Representative (also called Consumer Advocate)** – Consumer representatives/advocates are individuals who work at nonprofit, mission oriented organizations that represent a specific constituency of consumers or patients; their primary emphasis is on the needs and interests of consumers and patients.
 - **Consumer advocates are distinguished from other stakeholders because they:**
 - Do not typically have financial stake in the health care system
 - Are a trusted source of information in the community
 - Speak from a global perspective and have experience representing the diverse needs and wants of groups of consumers and patients
 - Have networks to empower and mobilize the community (e.g. email lists, websites, meetings, newsletters, and conferences) and share information and messages
 - Have established relationships with the media, policymakers, and elected officials

National Partnership for Women and Families – Aligning Forces for Quality

- Some good core competencies to look for:
 - Experience advocating the patient viewpoint
 - Background in health care or understanding of the health care system
 - Communication skills and ability to “tell a story”
 - Experience serving on multi-stakeholder groups
 - Baseline knowledge of the technical components of health care quality

- Examples of Consumer Advocacy Organizations
 - Organizations serving specific constituencies such as women, children, older adults, minority patients and workers, such as the YWCA, AARP, NAACP and AFL-CIO
 - Disease specific organizations, such as the American Cancer Society, American Diabetes Association, American Heart Association and the National Kidney Foundation
 - Faith-based organizations, such as churches, mosques and synagogues
 - Broad-based or policy-focused organizations, such as Citizen Action, Consumers Union, League of Women Voters and Literacy Councils.

Australian Government

- Principles for the Appointment of Consumer Representatives: A process for Governments and Industry*
 1. Appointments must be made on merit
 2. Appointments must be independent of industry or government
 3. Consumer Organizations must be involved in the appointment
 4. A wide range of candidates should be sought
 5. The appointment process must be consistent with good corporate governance
 6. The appointment process must be transparent, accountable, and cost effective
- Nominees must be:
 - Capable of reflecting the viewpoints and concerns of consumers
 - Persons in whom consumers and consumer organizations have confidence
- As a minimum, candidates should demonstrate the following:
 - Expertise in consumer affairs
 - Links to relevant consumer organizations
 - Capacity and willingness to consult with relevant consumer organizations
 - Knowledge of, or the ability to acquire knowledge of, the industry/issues involved in the appointment

U.S. Food & Drug Administration

- **A key method of ensuring that FDA gets consumers points of view is by including consumer representatives on Agency advisory committees.**
- **The role of the consumer representative is to:**
 - Represent the consumer perspective on issues and actions before the advisory committee.
 - Serve as a liaison between the committee and interested consumers, associations, coalitions, and consumer organizations.
 - Facilitate dialogue with the advisory committees on scientific issues that affect consumers.
- **To qualify, a consumer representative must be able to analyze scientific data, understand research design, discuss benefits and risks, and evaluate the safety and efficacy of products under review.**
- **It is also essential that the representative have an affiliation with and/or active participation in consumer or community-based organizations.**
- **Consumer nominations require**
 - cover letter
 - *curriculum vitae* or resumé (including the nominee's home and business address, telephone number, and e-mail)
 - name of the consumer or community-based organization(s) for which the nominee can demonstrate participation

“Straw” Person Definition of Consumer - Discussion

➤ Suggested “Straw” Person Requirements

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 - Others?

Definition – Meaningful Access

➤ **Merriam-Webster**

- Pronunciation: \ ăk- ses-also ik- ses \
- Function: *transitive verb* Date: 1962
- : to get at : gain access to <accessed the computer by phone>

➤ **Meaningful Use NPRM – “...timely access to data, knowledge, and tools to make informed decisions and to manage (patient and families) health**

➤ **“Meaningful” Access – Components of definition**

- Timely
- Not cost-prohibiting
- Language/translation services
- Electronic and hard copy

➤ **Suggested “straw person”**

- Timely and affordable access to “data, knowledge, and tools,” through electronic and traditional media, that enable consumers “to make informed decisions and to manage their health”

Consumer Advisory Council – *Proposed*

- **Size**
 - Approximately 12 members
- **Membership**
 - No slots should be reserved
 - Ethnic, cultural, geographic, racial, payor and gender diversity
- **Nominating Committee**
 - Application and nomination process
 - Nominating committee members must not be up for re-appointment
- **Terms**
 - Staggered every three years after an initial one year term
 - Members may not serve more than two consecutive terms
- **Functions**
 - At least one Council member must serve on the Board of the Statewide HIO
 - Provide and cultivate recommendations for Board members to the Nominating Committee
 - Bi-directional communication between the Statewide HIO and the community
 - Provide community input and review into Statewide HIO communications planning and consumer-facing campaigns
 - Reports to the Executive Director of the Statewide HIO and “consumer” Board members

Consumer Engagement Strategy – DRAFT

Activity	Details/Workplan	Cost	Timeline
Convening roundtables and focus groups to gain consumer feedback	<ul style="list-style-type: none"> ➤ Develop materials for review ➤ Identify and recruit consumers ➤ Host roundtables ➤ Analyze feedback and share with Council and Board 	Staff support and materials; incentive	Mid-2010
Ensuring consumers have strong representation on the Board of the Statewide HIO	<ul style="list-style-type: none"> ➤ Provide guidance for Nominating Committee bylaws ➤ Appoint consumer representatives 	Minimal	Mid-2010
Appointing a dedicated consumer advocacy staff member to manage and coordinate daily activities	<ul style="list-style-type: none"> ➤ Create job description for staff member ➤ Conduct interviews ➤ Select and train candidate 	Annual Salary	Mid-2010
Appointing a Consumer Advisory Council to provide ongoing input and review to the MO-HITECH Advisory Board and staff	<ul style="list-style-type: none"> ➤ Create description of roles and responsibilities for Council members for review and approval by staff/Board ➤ Identify applicants/nominees ➤ Conduct interviews ➤ Appoint candidates 	Staff support	Mid-Late 2010
Establishing funding resources to empower stakeholder organizations in consumer engagement	<ul style="list-style-type: none"> ➤ Identify potential funding sources ➤ Conduct informational interviews/meetings with funding sources ➤ Follow up and provide requested materials 	Staff support and materials	Ongoing
Conducting traditional and social media, and other public outreach campaigns to educate consumers; faith-based organizations and federally qualified health centers (FQHCs) are two potential vehicles of communication that may be used to reach non-traditional consumers	<ul style="list-style-type: none"> ➤ Identify and prioritize consumer-facing media campaigns for development and execution ➤ Identify communication channels and partners for messages ➤ Develop consumer resources/tools/messages and review with Consumer Advisory Council; modify as necessary based on input 	Material development	Ongoing

Project Milestones & Timelines

Operational Planning

Week	Key Topics & Discussions
3/10	<ul style="list-style-type: none"> ➤ Develop definitions of consumer and meaningful access ➤ Begin discussion of consumer engagement strategy
3/24	<ul style="list-style-type: none"> ➤ Develop draft work plan for consumer engagement strategy ➤ Develop draft budget for consumer engagement strategy ➤ Review draft outline/content for Operational Plan
4/7	<ul style="list-style-type: none"> ➤ Review and update work plan and budget ➤ Update from Finance and Legal/Policy Workgroups
4/21	<ul style="list-style-type: none"> ➤ Review and comment on draft Operational Plan
5/5	<ul style="list-style-type: none"> ➤ Review updated draft Operational Plan ➤ Review updated work plan and budget
5/19	<ul style="list-style-type: none"> ➤ Finalize Operational Plan ➤ Determine continuing activities and opportunities for engagement
5/31	<ul style="list-style-type: none"> ➤ Target completion date for Operational Plan

Next Steps

- **Consider Board nominees and send suggestions to ckrebs@primaris.org**
- **Provide feedback on “straw person” definitions**
 - Consumer
 - Meaningful access
 - Consumer Advisory Council
- **Provide feedback on Consumer Engagement activity components**
 - Workplan
 - Budget
- **Identify other consumer engagement initiatives for Workgroup review and consideration**
 - Send to ckrebs@primaris.org, 573 424-9174

**Next Meeting: Wednesday, March 24th
11:30 am – 1:30 pm
Jefferson City, MO**